

KU CENTER ON
DEVELOPMENTAL
DISABILITIES



STATE OF THE STATES
IN INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES

AD ASTRA PER ASPERA
Kansas
Department for Aging
and Disability Services



Institute for Health and
Disability Policy Studies

The University of Kansas

KUCDD/KDADS Waiting List Study Updates

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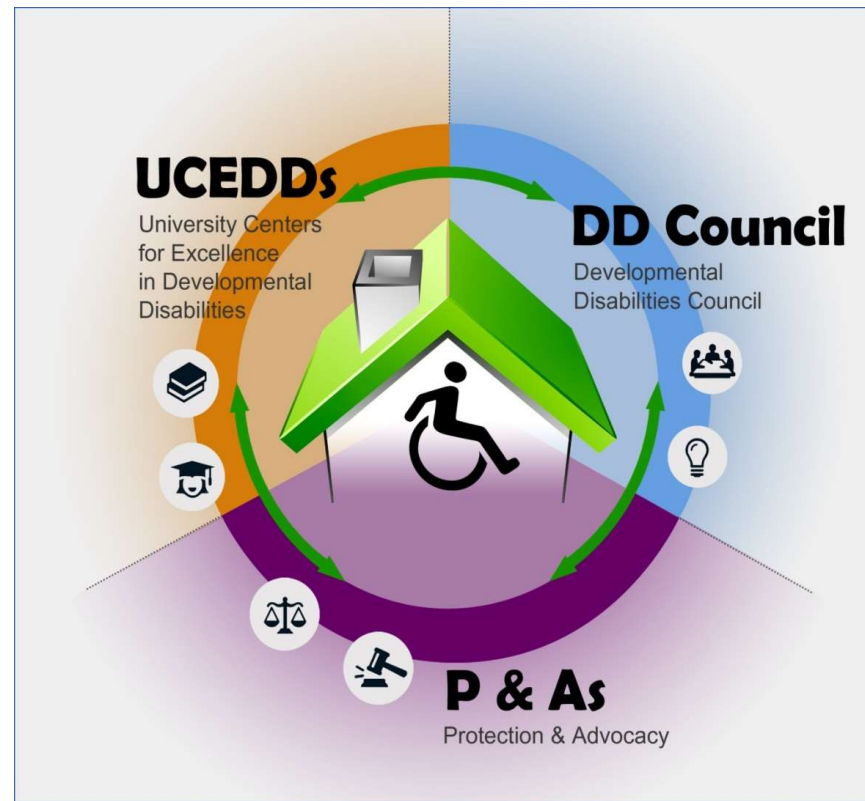
CENTER for RESEARCH on AGING & DISABILITY **OPTIONS**
CRADO
UNIVERSITY OF KANSAS • SCHOOL OF SOCIAL WELFARE

Purpose of UCEDDs Today

To provide leadership in, advise Federal, State, and community policymakers about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.

-DD Act, Sec. 153(a)(1)

DD Network in Each State



KUCDD Core Functions



Research, evaluation, public policy analysis



Training

Interdisciplinary pre-service training
Continuing education & community training



Community Services

Technical assistance
Model & demonstration services



Information Dissemination

Overview of Project

The goal of the project is to inform KDADS decision making regarding system capacity and reducing the waiting lists through two aims.

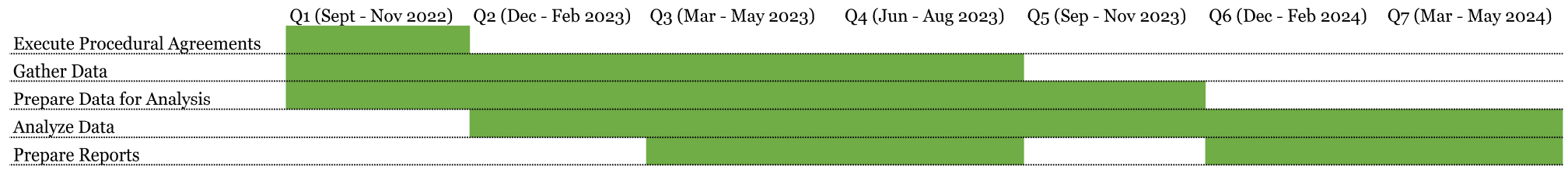
- Aim 1: Collect and Analyze Existing Waiting List Data
- Aim 2: Collect Information on needed supports of People on the Waiting List

Aim 1: Collect and Analyze Existing Data

The purpose of Aim 1 is to

- (1) Understand the overall makeup of people on the IDD and PD waiting lists to aid in planning for services that will meet the needs of people on the waiting lists, and
- (2) Create a predictive model for service needs and potential crisis exceptions, which will inform primary data collection as part of Aim 2.

Project Timeline: Aim 1



Initial results from Aim 1 - IDD

Number of people currently on the IDD waiting list as of December 6, 2022:

4831

Average Time on IDD Waiting List

5
Years

Maximum Time on IDD Waiting List

11
Years

Initial results from Aim 1 - PD

Number of people currently on the PD waiting list as of December 6, 2022:

2344

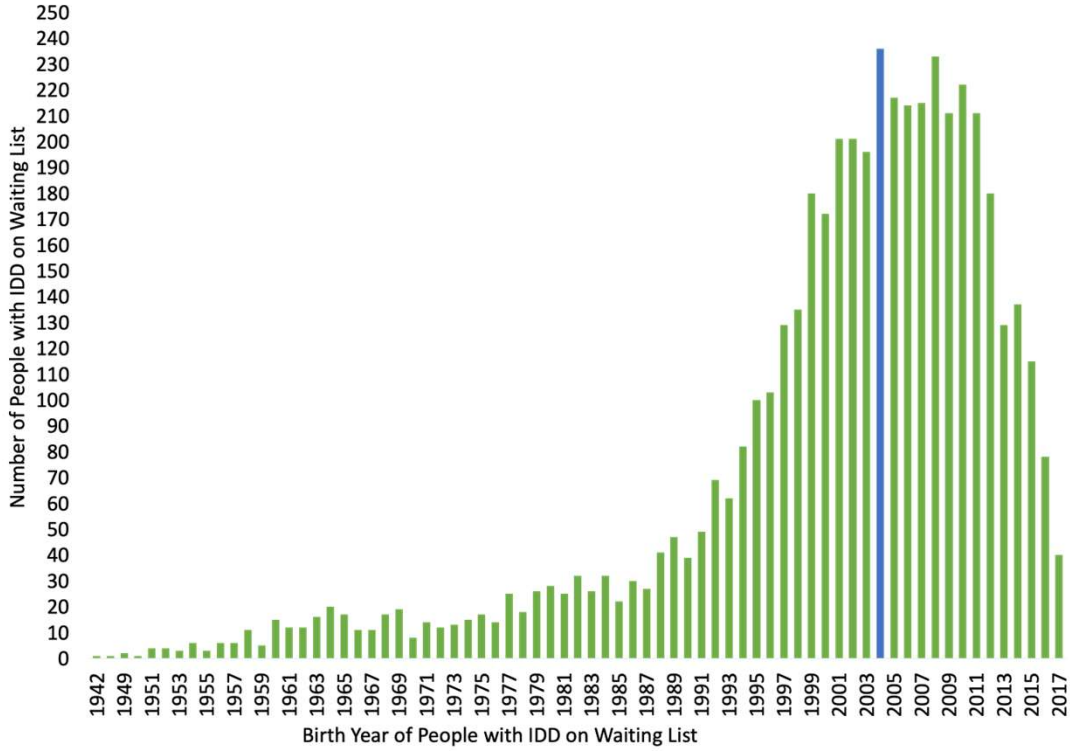
Average Time on PD Waiting List

1
Years

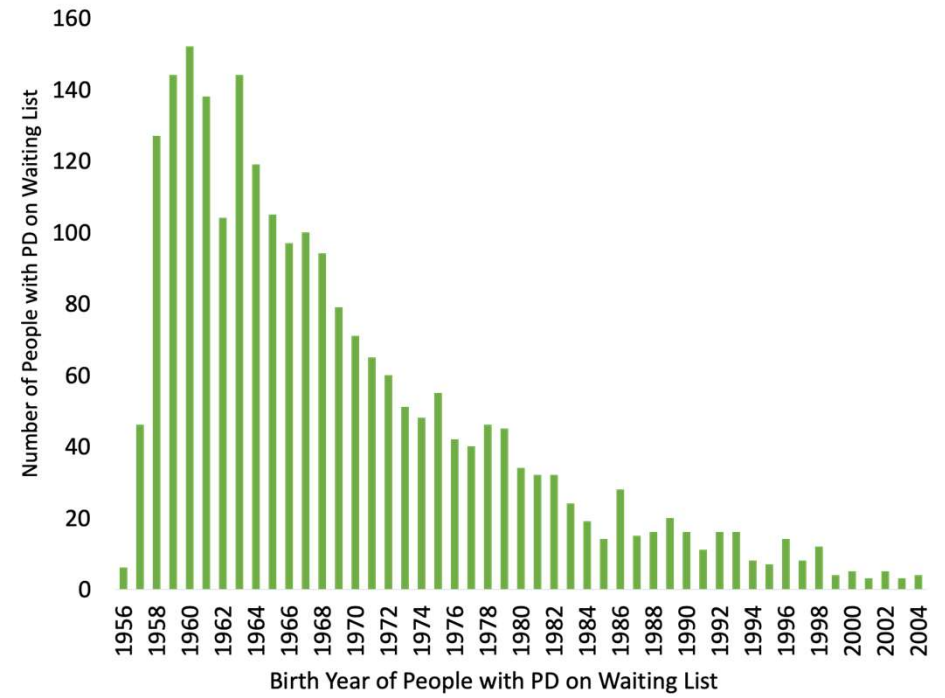
Maximum Time on PD Waiting List

3
Years

Birth Year of People on Waiting List



Birth Years of People with PD on Waiting List



IDD Reasons for Removal from Waiting List

Reasons for Waiting List Removal 2017-2022		
Reason	Number	Percent
Placed on HBCS Services	1920	50%
Unable to Locate/Contact	488	13%
Incorrect Waiting List	342	9%
Moved out of State	256	7%
Voluntary Removal	183	5%
No Longer Meets Long-Term Care Threshold	169	4%
Permanent Nursing Facility Placement	141	4%
Financially Ineligible	94	2%
Deceased	90	2%
No Longer Meets Program Eligibility Criteria	84	2%

PD Reasons for Removal from Waiting List

Reasons for Waiting List Removal 2017-2022		
Reason	Number	Percent
Placed on Home and Community Based (HCBS) Services	5809	52%
Unable to Locate/Contact	1929	17%
Deceased	911	8%
Permanent Nursing Facility Placement	799	7%
No Longer Meets Program Eligibility Criteria	700	6%
Refused Services	377	3%
Financially Ineligible	326	3%
Moved out of State	160	1%
Voluntary Removal	62	0.6%
Placed on MFP Grant Program	57	0.5%

Initial results from Aim 1

IDD – Yearly Crisis Exceptions	
Year	Crisis Exceptions
2017	184
2018	179
2019	205
2020	175
2021	156
2022	79

Reasons for entering IDD Waiver services through Crisis Exceptions 2021 and 2022		
Reason	Number	Percent
Caregiver Needs	83	15%
Significant Behavioral Support	68	12%
Criminal Justice Involvement	67	12%
Abuse, Neglect, Exploitation	59	11%
Supported Employment	44	8%
Division of Children and Families (DCF)/Foster Care Involvement	42	8%
Significant Physical Health Needs	36	7%
Mental Health/Emotional Support Needs	28	5%
Risk of Homelessness/Eviction	24	4%
Re-applications, Lost/No Medicaid	19	3%

Initial results from Aim 1

PD – Yearly Crisis Exceptions	
Year	Crisis Exceptions
2017	12
2018	16
2019	27
2020	217
2021	339
2022	344

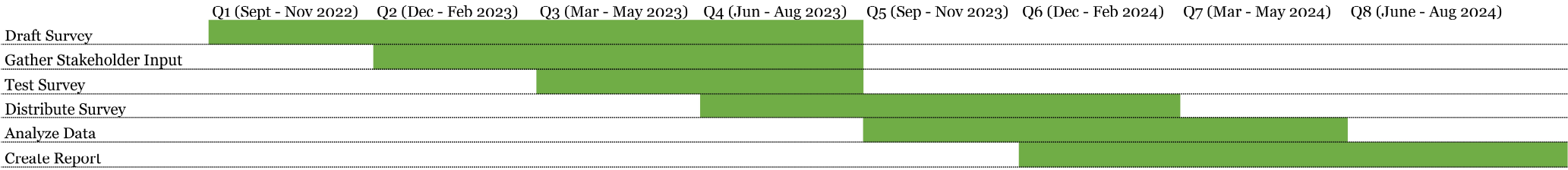
Reasons for entering PD Waiver Services Through Crisis Exceptions 2020-2022		
Reason	Number	Percent
Imminent Risk to NF	1084	86%
Terminal	124	10%
Adult Protective Services (APS) Determination	39	3%
APS Report	14	1%
APS Report Substantiated	4	0.3%
Domestic Violence	2	0.2%

Aim 2: Collect Survey Data

The purpose of Aim 2 is to collect data from people on the waiting lists to:

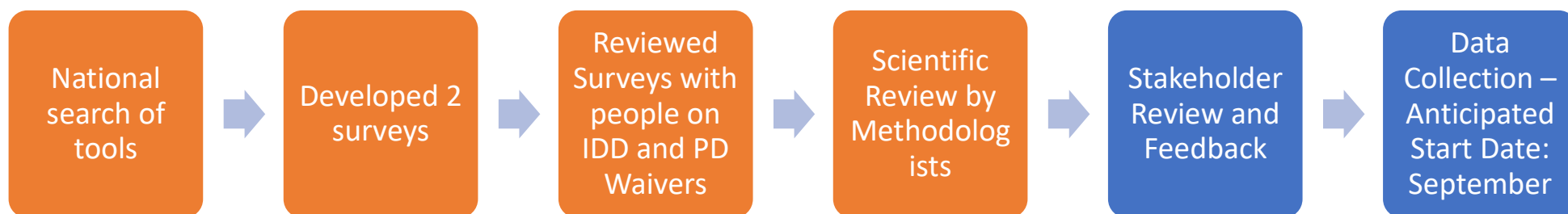
1. Understand the demographics, experiences, and needs of 1800 people on the IDD and PD waiting lists .
2. Using the predictive model created under aim 1, identify people at risk for entering services through a crisis exception in the next 3 to 5 years.
3. Forecast service and support needs at the CDDO and ADRC level up to 5 years out.
4. Identify important health, employment, community living, and support need trends of people on the waiting lists.

Project Timeline: Aim 2



Aim 2: Needed Supports Survey

Survey Development



Waiting List Surveys

Service and Supports Survey

- The purpose of this survey is to understand the supports people need to do the things they want and need to do in their life.
- 3 Sections
 1. Service Planning
 2. Support Planning
 3. Demographics

Caregiver Survey

- The purpose of this survey is to understand the needs of people who provide care for people on the IDD or PD waiver.
- 5 Domains
 1. Caregiving Responsibilities
 2. Needs of Caregiver and Person
 3. Needed Services
 4. Financial and Employment Impact
 5. Goals for the Person's Future
 6. Demographics

Plan for Survey Deployment

For people on the IDD waiting list

For people on the waiting list under the age of 14:

- Caregiver completes Service and Support Needs Survey
- Caregiver completes Caregiver Survey

For people on the waiting list over 14:

- Person on waiting list completes Service and Support Needs Survey with support as needed.
- Caregiver completes Caregiver Survey

For people on the PD waiting list

- Since so few people on the PD waiting list are under 16, we will administer the survey to only people over 16.
- Person on waiting list completes Service and Support Needs Survey with support as needed.
- Caregiver completes Caregiver Survey

Learning from Other States

Learning from Other States

- We reached out to states with current or recent waiting lists to learn more about waiting list characteristics, management and prioritization policies, and any efforts to reduce waiting lists
 - We identified states using Kaiser Family Foundation data
 - We asked each state to complete a brief survey about waiting lists characteristics, policies, and management strategies
 - Meetings with each other, hosted/moderated by KU, for further discussion
- We contacted 35 states with current or recent waiting lists for HCBS 1915(c) programs that serve individuals with intellectual and developmental disabilities (IDD)
 - 15 states responded: Alaska, Colorado, Georgia, Iowa, Indiana, Kansas, Kentucky, Mississippi, Nebraska, North Dakota, Ohio, Oklahoma, Pennsylvania, Utah, Wyoming
- We contacted 21 states with current or recent waiting lists for HCBS 1915(c) programs that serve individuals with physical disabilities (PD), drawing on KFF data
 - 10 states responded: Alabama, California, Iowa, Kansas, Michigan, Missouri, Montana, Nevada, Utah, West Virginia

Learning from Other States

- Across participating states, there are 16 IDD waivers with waiting lists
 - Waitlist size ranges from 1,700 to 8,277
 - Waitlist time length ranges from 1 year (1 state) to 10 years (2 states) (rough average of 6 years)
- Across participating states, there are 12 PD waivers with waiting lists
 - Waitlist size ranges from 1 to 7,995
 - Waitlist time length ranges from 1.5 months (1 state) to 22 years (1 state) (Most were in the 1-3 year range)
- Most waitlists are first-come first serve, with exceptions for crisis or priority need
 - The most common crisis/priority reasons were consistent across states: caregiver risks; abuse, neglect, exploitation; high risk behaviors; criminal justice system involvement (IDD), deinstitutionalization/institutional diversion; housing risks/homelessness; youth transitions (IDD); unmet basic health and safety needs
 - Some states have been successful in using a standardized assessment tool to help determine crisis/priority need, and we will be taking a closer look at these tools
- These are preliminary findings
 - a few states are still completing their survey

Learning from Other States

- Many states have other services and supports available to those on the waiting list
 - Other waiver services
 - State plan LTSS, such as personal care, nursing, and case management; these services are usually capped
 - State general fund or county funded services such as respite, caregiver compensation, family support payments; these are also limited/capped
 - Contract with entities that help education people about and connect them with to community resources
 - The following states have eliminated waiting lists in recent years: Alabama, Wisconsin, Missouri, North Dakota
- The following states are working towards eliminating their waitlists: Missouri, Nebraska, Oklahoma, Pennsylvania, Michigan, Utah



KUCDD

Kansas University Center on Developmental Disabilities



Thank you!

Let's Keep in Touch!



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